

Nurse developments in neuroendocrine tumour management

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Abstract

Nurse developments in the management of neuroendocrine tumours have changed significantly over the past three years. At the Royal Free Hospital we set up the nurse specialist role due to the expansion of patients being referred to the specialist unit, and the obvious need for a nursing input into their care. The nurse specialist can make a significant contribution within the context of a multidisciplinary team especially in the production of guidelines and policies to ensure and maintain high standards of practice, education for the patient, and the provision of expertise and security that the patient requires when diagnosed with a rare disease.

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Nurse developments in the management of neuroendocrine tumours (NETs) have changed significantly over the past 3 years. At the Royal Free Hospital we set up the nurse specialist role due to the expansion of patients being referred to the specialist unit, and the obvious need for a nursing input into their care. The nurse specialist can make a significant contribution within the context of a multidisciplinary team (MDT) and perhaps on a research/interest level within the context of the UK and European NET tumour groups – UKNET and ENET.

I joined the NET MDT at the Royal Free Hospital in 2000. The NET clinic had already been set up for 3 years, and the patient caseload at that time was approximately 100 patients.

To be a nurse specialist, one of the obvious requirements is to have an advanced knowledge of the field you are working in. For most of the common cancers, there is an abundance of information for both the nurse and the patient; however, within the speciality of NETs there is virtually nothing. I enrolled to do an Advanced Oncological Diploma in the hope that it would aid me in the daunting task ahead, but it is worth mentioning that although the course provided a lot of knowledge about the care of the cancer patient, NETs were not mentioned once. This highlighted the rarity of the disease and the lack of information that was available. Specific NET experience was gained from sitting in on clinics, attending ward rounds and meetings held by the MDT.

I aim to achieve a high standard of nursing care for the NET patient, but over the past 3 years two factors proved to be major challenges. First, the sense of isolation that could be felt by both the patient and the nurse; and secondly the lack of recognition and appropriate information about the disease. It was vital to make changes.

A major part of the nursing role is to be personally accountable for ensuring promotion, protection and the best interest of the patient. For the NET patient it is imperative that this is a number one priority. Not only are these patients diagnosed with a type of cancer with an unusual name – as one patient called it ‘a never ending tumour’, but there are many investigations and treatments that they have not heard of: ‘MIBG’ and ‘octreotide scans’, ‘chromogranin tests’ and ‘radionucleotide therapy’ are just a few examples. On top of this the patient is often seen by doctors from different specialities including gastroenterology, oncology, endocrinology, surgery and radiology. Patients would leave the clinic wanting information for themselves, friends and other family members; they wanted people to talk to, and in fact they simply wanted to understand. All the common cancers have well-established teams in both primary health care and hospital settings. Information is abundant and support groups seem to function effectively, alongside telephone help lines and heavily funded awareness campaigns. This was the level we wanted to achieve.

Change began with the primary goal being the patient and the overriding emphasis on their quality of life (QoL). Tests and investigations were organised and local and medical protocols for the management of NETs were put into place. QoL was monitored through questionnaires, namely the European Organisation for Research and Treatment of Cancer (EORTC) QLQ-C30, and an in-house NET proforma. It was requested that patients should complete these at every clinic visit. It was important that QoL was also documented before and after treatments. Currently the EORTC is developing a dedicated QoL questionnaire for NET patients, which is being validated.

At the Royal Free Hospital regular follow-up and monitoring was ensured, with an increase in clinics and multidisciplinary collaboration. More effective discharge planning was implemented, with a follow-up phone clinic one week after discharge, and detailed discharge summaries. A nurse-led clinic was set up giving easier and more frequent access for the patients. Local medication and treatment guidelines were set up and these will be endorsed by national guidelines from UKNETwork. Currently, nurses have been involved, with medical support, in developing a booklet targeting the primary health care teams to enable primary carers to have adequate information to participate in the shared care of these patients.

Local shared care guidelines, for primary care physicians, for the use of somatostatin analogues were also set up for use by the Royal Free Hospital. These guidelines contain information on the prescribing and giving of the medication, and disease information. A patient pack has also been developed and will be ready for distribution in September 2003. The pack includes a patient video, patient leaflet and information for family and friends. It also contains a useful diary card and lifestyle tips. Information sheets pertaining to individual treatments and investigations were developed for use at the Royal Free Hospital. There is also a separate telephone line that patients can call for advice and information – this is a mobile number that is in addition to the hospital contact numbers.

Patient and public awareness has increased, especially with the 'Quiet Cancer Appeal' launched in 2001. Various fund raising events have taken place – even pigeon racing! Events have been organised by the patients themselves, and this shows the commitment from the patients to develop a service that they truly rely upon. The patients have also set up a support group, named 'Living with Carcinoid'. The group offers support to patients with any type of NET.

Awareness amongst health professionals is also increasing with a yearly UKNETwork Neuroendocrine Tumour Conference, and teaching days for the nursing staff. There are now increasing numbers of nurses specialising in the care of this group of patients, and home care is becoming more possible with the development of long-acting somatostatin

analogues and an improvement in the relationship between the hospital and the primary health care teams.

There have been so many changes in the care of this patient group that at the Royal Free Hospital there is now an independent NET Unit, with a clinical fellow, a research fellow, two nurses and a basic science research team, all of whom work towards the ultimate goal of improving the patient's QoL.

There needs to be a formal collaboration of NET nurses nationwide that has the backing of a national organisation such as UKNET. With this in place any nurse who feels isolated will be able to find support and advice from others. On the medical side there are a number of clinical studies ongoing. Such clinical trials are imperative to ensure evidence-based practice and will also involve national and international collaboration.

With this approach to patient care the NET patient will feel secure and informed with the knowledge and support of the specialist team behind them, and the guidance and understanding of their primary health care team.

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